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Incomplete registration and reporting of culture-confirmed childhood tuberculosis diagnosed in hospital

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Setting: The South African National Tuberculosis Programme (NTP) recommends the registration of tuberculosis (TB) patients at community clinics. TB in children is often diagnosed at referral hospitals, and there are concerns as to whether these children are accurately reflected in routine NTP reporting.

Objective: To assess the completeness of registration of children with culture-confirmed TB diagnosed in a referral hospital, in the routine provincial electronic TB register (ETR.Net), and to describe TB treatment outcomes.

Design: A retrospective cohort study including children aged <13 years diagnosed with culture-confirmed TB at Tygerberg Children's Hospital from July 2007 to June 2009. Data on demographic, clinical and referral factors were collated from hospital data sources. Electronic matching was used to identify children in the provincial ETR.Net.

Results: Only 166 of 267 (62%) children were registered in ETR.Net. Children with TB meningitis and death prior to referral were significantly less likely to be registered. Treatment outcome data were available for only 70% of children; favourable outcomes were reported in 56%.

Conclusions: A large proportion of children diagnosed with confirmed TB at a referral hospital were not registered, resulting in underreporting of the burden and severity of childhood TB. Routine surveillance of childhood TB should include linkage of hospital data.

Routine surveillance is required by national tuberculosis programme (NTP) managers for decision-making and planning. If the quality of data is poor or incomplete, the burden and extent of tuberculosis (TB) may be inaccurately estimated, leading to poorly informed decisions and planning for TB prevention and treatment.

The South African NTP has adopted a decentralised model for TB care, encouraging routine diagnosis and treatment at community primary health clinics (PHCs).[1] In the Western Cape Province, South Africa, TB registers are kept at community clinics and at selected specialised TB hospitals where case-finding services are provided. Based on NTP guidelines,[2] TB patients should be registered and recorded at this level, irrespective of where the diagnosis was made. Health facility-based paper TB registers are captured monthly in electronic form (ETR.Net). Provincial and national reporting of TB surveillance data in South Africa has used ETR.Net since 2004.

Following diagnosis at a referral hospital, TB patients are usually referred to their local PHC for treatment, where they should be recorded in the TB register. Two previous studies from South Africa showed high rates of unsuccessful hospital-to-clinic down-referrals—21% in Gauteng and 31% in KwaZulu-Natal[3,4]—but these studies did not focus specifically on children. A study at five local PHCs in the Western Cape Province showed that 54 of 354 (15.3%) children with TB were not recorded in the facility-based TB registers. All of these children were diagnosed at the adjacent referral hospital and a high proportion had disseminated disease.[5] The nature of incomplete reporting and treatment outcomes was not documented in that study.

We were concerned about larger scale underreporting of hospital-diagnosed TB in children, and specifically whether reported provincial data underestimate the true burden and severity of childhood TB.

The aim of this study was to assess the completeness of registration in children with culture-confirmed TB diagnosed at a tertiary referral hospital in the provincial electronic TB register, and to describe their TB treatment outcomes.

METHODS

This was a review of routine information from health services collated through different sources using a retrospective cohort design.

Study setting

The Tygerberg Children's Hospital (TCH) in Cape Town, Western Cape Province, serves as a referral hospital for a large surrounding geographic area (30–40% of the provincial population). In 2007, the TB notification rate in the province was 994.2 per 100 000; children aged 0–13 years were reported to have contributed 17.1% of the burden, with a TB notification rate of 620/100 000 (unpublished data, Western Cape Department of Health). Bacille Calmette-Guérin (BCG) vaccination is routinely given at birth; coverage in 2005 was 99%.[6]

There is no routine in-hospital administered system or register to record children diagnosed with TB. A senior paediatrician at TCH (HSS) maintains a database of all children routinely diagnosed with culture-confirmed TB as part of ongoing TB surveillance, drug susceptibility testing (DST) surveillance and to ensure comprehensive clinical care.

Sources of laboratory and clinical surveillance data

All requests for *Mycobacterium tuberculosis* culture are sent to the in-hospital division of the National Health

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Laboratory Service (NHLS). Mycobacterial culture is routine (Mycobacterial Growth Indicator Tube liquid culture medium [MGIT] 960, BD, Sparks, MD, USA). All positive paediatric culture results are routinely labelled and stored by designated NHLS laboratory personnel, and communicated on a weekly basis to HSS. The folders of these children are routinely reviewed to collect relevant clinical and demographic data.

Following bacteriological diagnosis in the hospital, children are typically referred to other health care facilities for initiation or continuation of TB treatment and recording. Referrals are mostly to PHCs, but also to TB hospitals, secondary hospitals (down-referral) and, infrequently, medium-term chronic care facilities. All children who are referred to a PHC for TB treatment should receive an official referral letter to the clinic at discharge. A copy of the letter should be left in the child's TCH hospital folder. In most cases, culture results are only available weeks after discharge and referral. As part of hospital surveillance, HSS performs active surveillance for those children with positive mycobacterial isolates when a clinical diagnosis has not been made prior to discharge from hospital, to ensure initiation of appropriate anti-tuberculosis treatment, typically by a nurse practitioner at the local PHC.

Based on NTP guidelines, facility-based TB register data should be updated on a daily basis and the register quality validated before capture in ETR.Net. ETR data updates are performed monthly, and data are aggregated for quarterly reports. All patients who are diagnosed and started on drug-susceptible TB treatment regimens should therefore be recorded in the TB registers, and captured in ETR.Net. Patients diagnosed with multidrug-resistant TB (MDR-TB) from the outset are not entered into ETR.Net, as they have a separate surveillance system. If a patient is recorded in the TB register and started on first-line treatment, but is later found to have MDR-TB, the NTP guidelines state that the patient's treatment outcome should be documented as 'failed', and that the 'MDR-TB patient' column in the register should be filled in. In addition, such patients should be recorded in a separate paper MDR register that is also captured electronically.

Study population and eligibility

All children aged <13 years routinely diagnosed with culture-confirmed *M. tuberculosis* disease at TCH from 1 July 2007 to 30 June 2009 were included in the study. Although the World Health Organization (WHO) international guidelines recommend reporting TB in children aged 0–14 years,[7] we used 0–13 years as this is the classification used for paediatric care at our hospital. Following initial inclusion in routine clinical-laboratory surveillance, exclusion criteria were a diagnosis of MDR-TB prior to referral from TCH and referral to a different province for management. The rationale for exclusion of children with MDR-TB is that additional surveillance and specialised care services are required for this subpopulation (studies ongoing).

Summary of data sources, variables and definitions

The following sources were used for data collection: TCH electronic laboratory-based hospital surveillance database, TCH administrative department data, TCH hospital folders, available TCH notification records, TCH TB meningitis (TBM) home-based care programme records, discharge summaries of the local TB referral hospital (Brooklyn Chest Hospital) and the provincial electronic TB register (ETR.Net).

A comprehensive database was compiled that collated clinical, demographic and referral-process hospital data. A second electronic source of data was then obtained from the provincial health department, containing all TB patients registered in the provincial ETR.Net during 2007–2010. We used electronic probabilistic linking[8–11] software (Registry Plus™ Link Plus, Centers for Disease Control and Prevention, Atlanta, GA, USA) to identify all possible matches between the comprehensive hospital database and the database extracted from ETR.Net using an inclusive approach. The software was configured to use four demographic variables: name, surname, sex and age. Names and surnames were converted using the New York State Identification and Intelligence System (NYSIIS),[12] a phonetic coding system that allows for inconsistencies and variations in spelling.

All matches were manually and independently reviewed by two investigators, initially for correlation of demographic details, and second to review the accuracy of the TB episode data. If there was agreement on three of the four demographic variables, records were included for further review. Further comparison of dates was then completed for all matched records to ensure identical treatment episodes, again using an inclusive approach. If one of the dates in ETR.Net (registration, treatment start or treatment outcome date) matched the hospital consultation or culture dates, the child was included, allowing a window period of 2 months prior to the admission date and of 6 months after the date the culture results became available.

Data regarding age, human immunodeficiency virus (HIV) status, sex, reported household TB contact and current TB treatment were recorded from the hospital folders. TB cases were classified as pulmonary TB (PTB), including hilar and mediastinal lymphadenopathy; extra-pulmonary TB (EPTB); or both PTB and EPTB. We report separately on disseminated TB (miliary TB and TB meningitis).

TB treatment outcomes are reported according to international recommendations.[13] Treatment outcomes were classified as favourable (treatment completed/cured) or unfavourable (treatment failure, transferred out, died or defaulted). For the purposes of the present study, an additional category, 'not evaluated', was included. This category included treatment outcomes that were not recorded in ETR.Net, as well as children who were not registered in ETR.Net and for whom no treatment outcome data were available from additional hospital surveillance sources.

Statistical considerations

Analyses were descriptive, presenting actual numbers and percentages for categorical variables and median and interquartile ranges (IQRs) for continuous variables. Hypothesis testing was performed using the χ^2 or Mann-Whitney *U*-tests. $P < 0.05$ was considered statistically significant. We used the STROBE (strengthening the reporting of observational studies in epidemiology) guidelines for reporting.[14]

Ethical considerations

Ethical approval was obtained from the Research Ethics Committee of the Stellenbosch University (waiver obtained for informed consent), the Ethics Advisory Group of the International Union Against Tuberculosis and Lung Disease, the study hospital and the provincial and metropolitan health services.

RESULTS

During the study period, 291 children were diagnosed with culture-confirmed TB at TCH. Twenty-four were excluded: 22 were diagnosed with MDR-TB disease before discharge and two were referred to PHCs in another province. Evidence of registration in the provincial ETR.Net was found for only 166 (62%) of the 267 children. Demographic, clinical and referral process factors in relation to ETR.Net registration are summarised in Table 1. There was no

association between evidence of registration and the demographic variables age or sex.

The only clinical factors that were significantly associated with lack of registration were disseminated TB and death prior to referral. In a sub-analysis of children with disseminated TB this finding was retained in children with TB meningitis, but not in those with miliary TB. TB meningitis remained significantly associated with lack of registration even when children who died prior to registration were excluded from the analysis ($P < 0.01$). Ten children died before referral for treatment; all were absent from the ETR.Net and hospital notification records.

The type of consultation and duration of hospital admission were borderline significant as risk factors for non-registration. None of the other clinical factors considered, i.e., HIV status, type of TB disease (non-disseminated), reported TB contact history, current TB treatment at time of investigation or drug resistance, was associated with presence of registration in ETR.Net. Some referral process factors showed only borderline association (presence of clinic referral letter in the hospital folder, and hospital notification done), but the type of health care centre to which the child was referred was not associated with ETR.Net registration.

Table 2 describes TB treatment outcomes, first showing all outcomes for registered children as documented in ETR.Net and second, showing treatment outcome data on all identified children, including outcome data on non-registered children from additional surveillance sources (TCH surveillance database, TBM

TABLE 1 Demographic, clinical and referral process factors in relation to electronic registration of children with culture-confirmed TB at a tertiary hospital in Cape Town ($n = 267$)

	Not registered ($n = 101$) *n* (%)	Registered ($n = 166$) *n* (%)	*P* value
Demographic factors			
Age, months, median [IQR]*	25 [13–51]	23 [12–73]	0.870
Male sex	51 (50.5)	97 (58.4)	0.200
Clinical factors			
HIV status			
Tested	79 (78.2)	124 (74.7)	0.514
HIV-infected	21/79 (26.6)	35/124 (28.2)	0.798
HIV-infected, on HAART	8/21 (38.1)	15/35 (42.9)	0.726
Type of TB			
PTB only	39 (38.6)	71 (42.8)	0.612
EPTB only	21 (20.8)	27 (16.8)	
PTB and EPTB	41 (40.6)	68 (41.0)	
Disseminated TB	29 (28.7)	27 (16.3)	0.015
Miliary TB	12 (11.9)	16 (9.6)	0.562
TB meningitis	22 (21.8)	13 (7.8)	0.001
Deaths prior to referral†	10 (9.9)	0	<0.001
Reported TB contact history‡			
Household contact	42 (41.6)	77 (46.4)	0.099
Parent on TB treatment	24 (23.8)	40 (24.1)	0.918
On TB treatment at the time of consultation	5 (4.9)	5 (3.0)	0.419
Drug resistance			
INH monoresistance	5 (4.9)	7 (4.2)	0.928
RMP monoresistance	1 (0.9)	1 (0.6)	
Multidrug resistance	2 (2.0)	5 (3.0)	
Type of consultation			
Out-patient	16 (15.9)	41 (24.7)	0.087
In-patient	85 (84.2)	125 (75.3)	
Duration of hospitalisation, days, median [IQR]*§	16 [5–29]	3 [9–20]	0.052
Referral process factors			
Presence of referral letter in folder¶	17/31 (54.8)	68/93 (73.1)	0.058
Referral decision at discharge to#			
Community Health Clinic	58 (63.7)	125 (75.3)	0.100
TB hospital	26 (28.6)	28 (16.9)	
Secondary hospital	3 (3.3)	9 (5.4)	
Chronic medium-term care facility	4 (4.4)	4 (2.4)	
Hospital notification done	7 (6.9)	23 (13.9)	0.082

*Mann-Whitney *U*-test used for hypothesis testing.
†9 children died in hospital and 1 child died after discharge before culture results were available.
‡Known TB contact reported for 140/267 (52%) children.
§Data missing for 9/210 children admitted as in-patients.
¶Only for those children who were referred to PHCs for TB treatment at discharge from TCH 151/183; 21 folders were not available for review, and six children were already on TB treatment.
#The denominator here is 257 and not 267, due to the 10 children who died in hospital prior to a referral decision.
TB = tuberculosis; IQR = interquartile range; HIV = human immunodeficiency virus; HAART = highly active anti-retroviral therapy; PTB = pulmonary TB; EPTB = extra-pulmonary TB; INH = isoniazid; RMP = rifampicin.

TABLE 2 TB treatment outcomes of children diagnosed with culture-confirmed TB at a tertiary hospital in Cape Town, South Africa

	Treatment outcomes as documented in the provincial ETR.Net (n = 166) n (%)	Treatment outcomes for all children, including outcome data from additional hospital surveillance sources (n = 267)* n (%)
Completed/cured	134 (81)†	149 (56)
Defaulted	13 (8)	13 (5)
Failed	3 (2)	4 (2)
Transferred out	6 (4)	6 (2)
Died	2 (1)	14 (5)
Not evaluated	8 (5)‡	81 (30)§

*Additional treatment outcomes included for 28 non-registered children.
†Actual recorded breakdown: completed = 120, cured/completed = 10, cured = 4.
‡Treatment outcomes not recorded in ETR.Net (n = 8).
§Includes children with no recorded treatment outcome in ETR.Net (n = 8), and children not registered in ETR.Net for whom no outcome data were available from additional hospital surveillance sources (n = 73).
TB = tuberculosis; ETR.Net = electronic TB register.

home-based care programme records and discharge summaries of the local TB hospital [Brooklyn Chest Hospital]). Treatment outcomes were available for only 70% of the children, and favourable treatment outcomes were documented in only 56%. Clinical characteristics, referral process factors and mortality data are described in Table 3.

TABLE 3 Clinical and referral process factors among children with culture-confirmed TB and documentation of death (n = 14)

	Deaths (n = 14) n (%)
Age, months, median [IQR]	26 [9–84]
HIV-infected*	4 (29)
HIV-infected on HAART	0
Drug resistance	
Rifampicin monoresistance	1 (7)
Multidrug resistance	2 (14)
Type of TB	
PTB only	4 (29)
EPTB only	1 (7)
Both	9 (64)
Disseminated TB†	7 (50)
Miliary TB	4 (29)
TB meningitis	5 (36)
Referral decision at discharge to	
Community health clinic	2 (14)
TB hospital	1 (7)
Secondary hospital	1 (7)
Deaths prior to referral‡	10 (71)
Source of mortality recording	
Hospital surveillance	13 (93)
ETR.Net	2 (14)
Recorded in both	1 (7)

*HIV status unknown (n = 2).
†Children with both miliary TB and TB meningitis (n = 2).
‡Nine children died in hospital and one child died after discharge before culture results were available.
TB = tuberculosis; IQR = interquartile range; HIV = human immunodeficiency virus; HAART = highly active antiretroviral therapy; PTB = pulmonary TB; EPTB = extrapulmonary TB; ETR.Net = electronic TB register.

DISCUSSION

This study confirmed our hypothesis that a large proportion of children with culture-confirmed TB diagnosed at a large tertiary level hospital are not recorded and registered in ETR.Net, and are thus not included in provincial, national and, consequently, international TB reporting. Children who were not registered more frequently had serious forms of disease and were more likely to have died. This implies underestimation not only of the burden of childhood TB in this setting, which is already high, but also of TB-related morbidity and mortality in children. The study further indicates that reported TB treatment outcomes in children may be inaccurate. Although treatment outcomes were favourable in more than 80% of those recorded, it does not take into account that data on approximately 40% of children were not captured, and that these children may be a group at high risk for unfavourable TB outcomes.

To our knowledge, no other studies in South Africa have accessed ETR.Net data at the provincial level and used electronic matching to evaluate the completeness of registration of childhood TB.[3,4,15,16] We used the actual source electronic data routinely used for TB reporting in our province, and were not limited in accessing only selected facilities and their registers. We were therefore able to identify all children who were registered, irrespective of the facility where they accessed care.

As the data collected at TCH form part of ongoing clinical care and research, the quality of this source of routine data was good, with negligible missing data. Unfortunately, data from ETR.Net are captured from TB registers, and there are some concerns regarding quality. Examples of problems identified were inconsistencies between treatment duration and treatment outcome (e.g., recorded treatment duration of only 2 months, with a treatment outcome documented as cured/completed), and incorrect classification of treatment outcomes (e.g., children with MDR-TB who were not classified as 'failed'). We were not able to verify true outcome data in this retrospective study; future prospective studies should address this aspect systematically.

It is important to note that our data do not necessarily reflect poor individual clinical care, but demonstrate limitations in the existing surveillance systems linking key data from a large hospital with recording and registration to the decentralised model. On the pathway from diagnosis at hospital level to registration in ETR.Net, we have to consider three processes. First is the hospital-to-clinic referral process, second is accurate recording of registration and treatment outcome data in the TB register at facility level, and third, accurate capture of the information recorded in the paper register into ETR.Net. Further studies are required to assess these individual components of the surveillance cascade.

Although our study could not identify any specific factors associated with non-registration in relation to the hospital-to-clinic referral process, previous literature has shown that this process is likely to be responsible for a substantial amount of non-registrations. Two previous studies from South Africa showed significant loss specifically during this process.[3,4] As a diagnosis of TB is made in, and the referral done from hospital, it should be the responsibility of the hospital personnel to ensure access to care at the PHC. Thereafter, PHC personnel are responsible for care, including accurate registration as part of monitoring and evaluation in the NTP. Improved systems to capture hospital-to-clinic referral and continuity of care for childhood TB are therefore critically important.

In our setting, children diagnosed with TB meningitis follow a different treatment path after the initial months of treatment. Some are referred to TB hospitals for the first few months

of treatment, while others are enrolled in a home-based care programme. These children are discharged home, but receive their treatment and clinical follow-up on a monthly basis from TCH until completion of treatment. Although these children are treated as out-patients, most of them will never attend a PHC for registration as they are treated only at the hospital. This highlights an additional gap in the processes linking hospital management and provincial registration systems. A possible way to solve this is to implement a hospital-based register specifically for children who are not likely to attend a PHC for treatment.

The association between a longer duration of admission and non-registration was interesting. We speculate that children with longer hospitalisation are likely to be more ill, with more severe forms of TB disease, and treatment is most likely started during hospital admission. This implies a lower probability of clinic-based management during the initial months of treatment and thus, possibly, also of clinic-based registration. It is possible that clinic staff might assume that children who were started on treatment in the hospital had already been registered. In contrast, children with a short period of hospitalisation will probably not start treatment in hospital but will be referred directly to a clinic for initiation of treatment.

As this was an operational study focusing on routine data, the study had several limitations. We only had access to data on children diagnosed with culture-confirmed TB, which represents only 30–40% of all children diagnosed with TB at TCH. Although we included all provincial records, we do not know if non-registered children sought care in a different province or from private practitioners. With record matching the most important consideration was not to miss true registrations, and thus an inclusive approach was used. Children aged 13–14 years were excluded due to local classification systems, but this could have resulted in further underestimation of the burden of disease. The natural history of disease shows that adolescents (especially girls) are at high risk of disease progression.[17] This study was not able to establish the specific reasons for non-registration or verify data sources between PHCs and ETR.Net, and future research is needed to evaluate these processes.

Our findings have implications for all three data-linking processes in the surveillance cascade. The hospital-to-clinic referral system could be improved by implementing a dedicated monitoring and follow-through service in the hospital. An in-hospital TB Care Centre has been shown to significantly improve referral success in Johannesburg.[18] NTP managers should monitor the quality of recording and registration regularly by verifying data using clinic records, TB registers and ETR.Net entry to ensure that accurate data are collected for TB reporting.

In conclusion, we found that almost 40% of the children diagnosed with culture-confirmed TB at a tertiary referral hospital were not included in ETR.Net, resulting in underreporting of the burden and severity of TB and TB deaths in South African children. Routine surveillance of childhood TB should include linkage of hospital data.

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Contexte : Le Programme National contre la Tuberculose (PNT) de l'Afrique du Sud recommande l'enregistrement des patients tuberculeux dans les dispensaires de la collectivité. C'est dans les hôpitaux de référence que le diagnostic de la tuberculose (TB) est souvent porté chez les enfants et des préoccupations existent concernant le fait que ces enfants soient ou non inclus de manière précise dans les déclarations de routine du PNT.
Objectif : Evaluer le caractère complet de l'enregistrement des enfants atteints d'une TB confirmée par la culture et diagnostiquée dans un hôpital de référence vers le registre provincial électronique de routine (TB) (ETR.Net), et d'autre part décrire les résultats du traitement de la TB.
Schéma : Etude rétrospective de cohorte comportant des enfants âgés de <13 ans chez qui une TB confirmée par la culture a été diagnostiquée à l'Hôpital des Enfants de Tygerberg entre juillet 2007 et juin 2009. On a rassemblé les données démographiques, cliniques et les facteurs de référence à partir des sources de données de l'hôpital. On a utilisé la corrélation électronique pour identifier les enfants dans le réseau ETR.net de la province.
Résultats : N'ont été enregistrés dans le réseau ETR.Net que 166 des 267 enfants (62%). On a noté que les enfants atteints de méningite TB et décédés avant leur transfert étaient enregistrés de manière significativement moins fréquente. Les données de résultats du traitement ont été disponibles chez 70% des enfants seulement. On a signalé des résultats favorables chez 56% d'entre eux.
Conclusions : Une proportion importante des enfants chez qui une TB confirmée a été diagnostiquée dans un hôpital de référence n'ont pas été enregistrés, ce qui entraîne des sous-déclarations du fardeau et de la gravité de la TB infantile. La surveillance de routine de la TB infantile devrait inclure un lien avec les données hospitalières.

Marco de referencia: El Programa Nacional contra la Tuberculosis de Sudáfrica recomienda el registro de los pacientes tuberculosos en los consultorios comunitarios. En el caso de los niños, el diagnóstico de tuberculosis (TB) se suele establecer en los hospitales de referencia y existen dudas sobre su inclusión en los informes corrientes del programa nacional.
Objetivo: Se buscó evaluar la exhaustividad del registro electrónico corriente de TB de la provincia (ETR.Net), con respecto a los casos de niños con TB confirmada por cultivo que se diagnostica en un hospital de referencia y se describió además el desenlace del tratamiento antituberculoso.
Método: Fue este un estudio retrospectivo de cohortes, en el cual se incluyeron los niños con diagnóstico de TB confirmada por cultivo en el Hospital Infantil de Tygerberg entre julio del 2007 y junio del 2009. Se recogieron los datos personales, los datos clínicos y los criterios de remisión a partir de las fuentes hospitalarias de datos. Mediante una comparación informatizada de los datos se verificó la notificación de estos casos en el registro ETR.Net de la provincia.
Resultados: Solo 166 de los 267 niños (62%) estaban notificados en ETR.Net. La probabilidad de registro de los casos de meningitis tuberculosa y de los niños que fallecieron antes de la remisión fue significativamente menor. Se obtuvo información sobre el desenlace terapéutico de solo 70% de los niños; se notificó un desenlace favorable en el 56% de los casos.
Conclusiones: Una gran proporción de los niños con diagnóstico confirmado de TB en el hospital de referencia no se encuentra notificada en ETR.Net, por lo cual existe una subestimación de la carga de morbilidad por TB y de la gravedad de la enfermedad en los niños. La vigilancia corriente de la TB de los niños debería comportar un vínculo con los datos hospitalarios.

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